UNDERSTANDING HEALTH CARE TRANSITION



"Don't call me a teenager. From now on, I want to be referred to as a pre-adult." Megan Curran, MD
Pediatric Rheumatologist
Ann & Robert H. Lurie
Children's Hospital
of Chicago

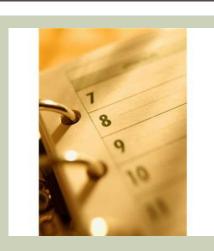
Presentation courtesy of: Rebecca Boudos, LCSW Spina Bifida Clinic Transition Specialist

Parag Shah, MD Chronic Illness Medical Director

OBJECTIVES

What do we mean by "Transition"

Facts, Challenges, Barriers



Implementing Transition

Tips and Resources

TRANSITIONS

HEALTH CARE TRANSITION

"the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult-oriented health care systems."

(AAP Clinical Report 2011)

KNOWN BARRIERS

- Pediatric Providers have reported
 - Lack of adult physicians to care for young adults with chronic illness
 - Lack of adult physicians with knowledge of pediatric diseases
 - Poor reimbursement
 - Their own reluctance



KNOWN BARRIERS

Adult Providers have reported

- Lack of training
- Difficulty meeting psychosocial needs
- Lack of time and reimbursement
- Lack of coordinated transfer from pediatric practices

Families and Patients have reported

- Differences in culture between pediatric and adult health care models
- Nervousness about going to somebody that "doesn't know anything about me"



PEDIATRIC VS ADULT MODELS OF HEALTH CARE

Pediatric

- Provider & parent controlled
- Comprehensive, multi-disciplinary clinics (one-stop-shopping)
- Case management & social work support
- Families supported through process

Adult

- Patient responsible
- Multiple providers each caring for separate issues
- Less social work or case management assistance
- Patient must be proactive to get services

GENERAL APPROACH TO TRANSITION PROGRAMS

SIX CORE ELEMENTS FOR PROVIDERS

- 1. Develop a transition policy
- 2. Identify youth that are going to be difficult to transition
- 3. Assess youth for transition readiness CHECKLIST
- 4. Develop tools for transition
 - a. Portable medical summary
 - b. Emergency plan
- 5. Transfer care
 - a. Summary
 - b. Communication with new provider
 - c. Condition fact sheet if necessary
- 6. Completion of Transition

 Continue to be a resource for patient and adult provider

WHEN SHOULD TRANSITION BEGIN?

- Ages 11-13
- Youth most receptive to future planning
- Less gap between peers



STEP 1: HEALTHCARE PROVIDER'S TRANSITION POLICY

- Timeline
 - Initiation
- Outcomes
 - What should the youth know and do before they leave the office
- Transfer
 - Practice processes
 - Communication

STEP 3: ASSESSING AND PREPARING YOUTH

- Knowledge
- Skills
- Responsibilities

USE A CHECKLIST TO HELP

CHECKLIST EXAMPLES

Completed by.					
Transition Checklist for Teens					
This Transition Checklist for Teens is about the skills you need to learn to t	ake care of	your healt	h when you become	me an adult. Y	our
doctor or nurse will talk with you about the areas where you want help. Pleas describe you the best. If you do not understand a question, please ask your please ask your please.				e box or boxes	that
ACCESSING HEALTH CARE - Skills and Abilities:	YES, I do	NO, I will learn	Someone will need to do this for me	N/A, Will not be needed	Need more info
△ Do you wear or carry a medical alert (list of allergies, conditions)?					
△ Do you speak up for yourself in your doctor's office?	ΤĒ			П	Ī
△ Do you help make health care decisions with your family or doctor?					
△ Do you see your doctor without your family/parents in the room?					
☐ Do you know your rights to keep your health information private?					
☐ Do you call your doctor(s) on your own if you have a problem?					
☐ Do you know how to schedule your own doctor appointments?					
Do you have an updated portable medical summary and/or care plan?					
Do you have an adult doctor (or a doctor for while you are at college)?					
MANAGING YOUR CONDITIONS AND TREATMENTS - Skills and Abilities:					
Do you know how to describe your own health conditions/disabilities and do you know how they affect your daily life?					
☐ Do you know the names of your medicines and why you take them?					
☐ Do you know what can happen if you skip your treatments or medicine?					
Do you almost always take your medicines correctly on your own?					
 Do you know when and how to fill your own prescriptions (knowing who prescribed and where to call, getting refills on time)? 					
O Do you use and take care of your own medical equipment and supplies?					
 Do you know when to call for routine checkups, urgent care, and when to go to the emergency room or call 9-1-1? 					
STAYING HEALTHY - Skills and Abilities:					
△ Do you know how to maintain a healthy lifestyle (diet, activity, etc.)?					
△ Do you understand how smoking, drinking, and/or using drugs can affect your condition (worsen symptoms, react with your medicines)?					
Do you know how your condition affects sexuality (the need for closeness, caring, and touch, sometimes involving sexual activity)?					
Do you know what you'll do for birth control, safe sex, and reproductive concerns (genetics, pregnancy)?					
INSURANCE - Skills and Abilities:					
☐ Do you know how to use your health insurance benefits (co-pays, referrals)?					
O Do you know who to call for questions about your insurance coverage?					
O Do you know how you will maintain health insurance as an adult?					
OTHER AREAS OF TRANSITION - Skills and Abilities:					
Do you know what you will do after high school (job, more school, recreational options, volunteer, etc.)?					
Do you know of resources that can help you to find adult services (job support, transportation, assistive technology, etc.)?					
☐ Do you know how your condition might affect your job choices?					
 Do you know what government benefits you might qualify for (SSI, SSDI, Health Benefits for Workers with Disabilities, Home & Community Based Services, etc.)? 					
Do you know about guardianship or power of attorney for health care?					
O Do you know your options for housing as an adult (on your own, group home)?					

KEY: △ ET □ MT ○ LT

See transition resources at end of slide presentation

KNOWLEDGE WHAT DO YOUTH WANT TO KNOW

- What to do in an emergency
- Learning to stay healthy
- How to get health insurance
- What could happen if condition gets worse

KNOWLEDGE

- Name of condition
- Symptoms of condition
- Names of medication and purpose
- Names of doctors and purpose
- How risk taking behaviors may affect medical condition
- Where to go in an emergency
- Basic information on insurance plan



EXAMPLES - KNOWLEDGE

- A pediatric rheumatologist is about to transfer care of a patient to a new adult doctor. What are some things the doctor can do to ensure the patient knows about their condition?
- Have patient describe their illness in 3 sentences
- Have them learn about their medical history from their parent, major hospitalizations, surgeries, medicines etc.
- Have patient create a portable medical record

SKILLS

- Speak directly to your medical team
- Meet alone with your medical team
- Call the nurse yourself
- Make an appointment
- Manage self care and medical skills
- Fill a prescription or medical supplies
- Take medications



EXAMPLES - SKILLS

- It has been a year since your last appointment with your specialist. Your doctor wants to start teaching you to become more independent. What can your doctor do?
- Speak directly to patient so they can learn to communicate
- Direct patient to front desk to make the appointment themselves
- Have patient prepare some questions to ask the doctor about their condition

RESPONSIBILITY

- Gradual shift in responsibility from caregiver to teen
- Teen going from consultant to manager to CEO
- Following recommendations to medical treatment (medications, regimens, restrictions)
- Take ownership of your body

THE SHARED MANAGEMENT MODEL

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M	id	dle
L	ate	

)	Provider	Parent/Family	Young Person
	- Major responsibility	-Provide care	-Receives care
е	-Support to parent/family & child/youth	-Manages	-Participates
	-Consultant	-Supervisor	-Manager
	-Resource	-Consultant	-Supervisor

Gall, Kingsworth, and Healy, 2006

EXAMPLES - RESPONSIBILITY

- Your doctor is trying to encourage you to become more adherent with your medical treatment. What can your provider do?
- Ask directly about barriers
- Use resources (technology, pill boxes) to help improve compliance

ASSESSMENT OF YOUTH

- Guardianship
- Insurance, benefits, and future financial planning
- Patient confidentiality rights
- Community Resources
 - Community participation has strong association with successful transition
 - Pediatricians may not know about community resources that are available
- Career/Vocation support

STEPS 4 AND 5: TRANSFER OF CARE WHAT DO ADULT PROVIDERS WANT

- •95% written summary and support from specialists,
- ■91% want to speak w prior provider,
- 84% written educational info about condition

Peter, N. G., C. M. Forke, et al. (2009). "Transition from pediatric to adult care: internists' perspectives." <u>Pediatrics</u> **123**(2): 417-23.

PORTABLE MEDICAL RECORD

NAME

Address, Home Phone, Cell Phone, Email DOB 5/24/73 289-XX-XXXX ALLERGY: Sulfa Drugs, Adhesive Tape

- High intelligence (130 IQ), compliant patient, high tolerance to pain
- Incomplete Quad (has sensation), only movement left index finger 10 cm
 Need to explain EVERY procedure, when possible, ask for consent prior to doing
- If unable to talk => one blink = yes / two blinks = no Read his lips OR letter/word board to direct his care.

HEIGHT 4'3" (51inches) WEIGHT 80lbs approx NEURO/MUSCULAR Spinal Muscular Atrophy Type 2 (Severe Anterior Horn Cell disease, 3/74) incomplete quad (has full sensation), no functional movement RESPIRATORY Respiratory failure - trach and vent (9/01), Chronic RLL Atelectasis, V44 Trach, 518.81 Respir Failure Recurrent pneumonia (last hospitalization, 9/01) Respiratory insufficiency, poor residual functions and reserved capacities GASTRO Decreased esophageal motility, s/p feeding gastrostomy tube (7/83) Severe deformities: thoracic, pelvic obliquity, bilateral dislocated hips ORTHOPEDIC flexion contractures, spinal fusion (3/82 Lueke Rod), pectus excavatum UROLOGICAL

Undescended L testicle (since birth), intermittent cath (10/01), cath: 10 Fr, Cystoscopy/left ureteral stent (10/01), IVP (6/90) A + (positive) IV: Porta Cath (10/24/01) RIS right clavicle (PC 0603880 - lot 36H1124)

SPECIAL NOTES

MEDICAL

Barbara XXXXX RN, AP, Ocala, FL O: 352-xxx-xxxx	HOSPITAL	4/95, 1/97, 5/0	onal Medical Center 01, 9-10/01	, Gainesville, FL
INTENSIVIST: Melvin XXXX, MD, Ocala, FL O: 352-622-xxxx	IMMUNIZATIONS	Flu 02 DPT 73, 79 TB 78, 87	Pneumo 79, 01 Measles 74	Tetanus 85 Mumps 74
PULMONOLOGIST: Robert xxx MD, Gainesville, FL O: 352- xxx -xxxx Bpr: 352- xxx -xxxx	ENTERAL		237ml) x 2 cans, noct	turnal 70 ml/hr
MEDICATIONS	HERBS / DRO	PS	VENT / TRA	сн/02
Rx	Lymphatic File Balancing Respiratory A Allertox –airborn File Balancing Author of the Balancing Author of the Balancing Acute Rescue Urinary Uninary Uninary Muscular Muscular Hingumentary Er Cheng Tang	5 2X 10 2X 7 2X 5 2X 3 3x 10 4x 6 2X 5 2X 8 2X 3 2X 5 2X 8 2X 1 tsp 2X	TRACH: Shiley 6	EAKING VALVE: sy-Muir PMV007
	SUDANCE			
IN	SURANCE	The state of the s	The state of the s	·

BlueCross BlueShield of Massachusetts BC/BS PPO Plan Code 200 Customer service: 800-296-xxxx XXP XXXXXXX 10 PPO

BLOOD TYPE

ACHDUNCTURE DUVSICIAN

BlueCross BlueShield of Massachusetts

Secondary Subscriber: xxxxx xxxxx BC/BS Blue Choice Plan 2, POS Code 200 Customer service: 800-222-xxxx XX XXXXXXXX 10

HEALTH SURROGATE c 352-xxx-xxxx

800-392-xxxx BC/BS Case Manager Option Care 800-825-xxxx 352-373-xxxx acc't. # xxxxx Home Nursing Agency House Calls 352-xxx-xxxx acc't. # xxxxx Pharmacy Bitting's

PORTABLE MEDICAL SUMMARY

Name: Address: City, State, Zip: Phone:

DOB: Gender: Male Allergies: Insurance:

Primary Diagnosis

Trimary Blagnosisi		
Age at Onset	Date of Onset	History

Other Diagnoses:

Age at Onset	Date of Onset	History

Other Diagnoses:

	Age at Onset	Date of Onset	History
1			

Current Medications:

Medication	Dose	Started	Response

Pact Medications

Medication	Dose	Started	Response	

Ailliuai Testilig.				
Test	Date	Result		

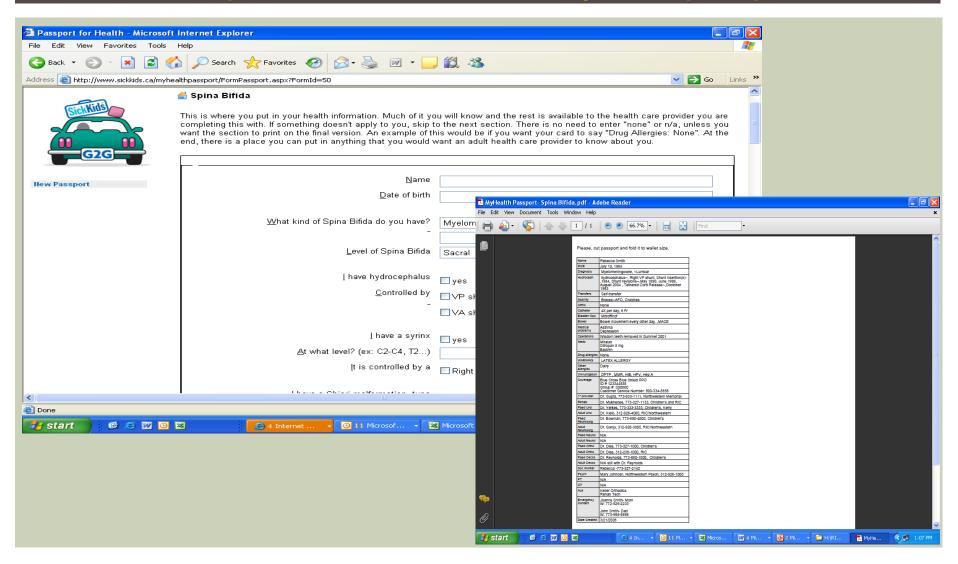
Medical Providers:

Na	ame	Specialty	Contact No.

7/28/09 AR

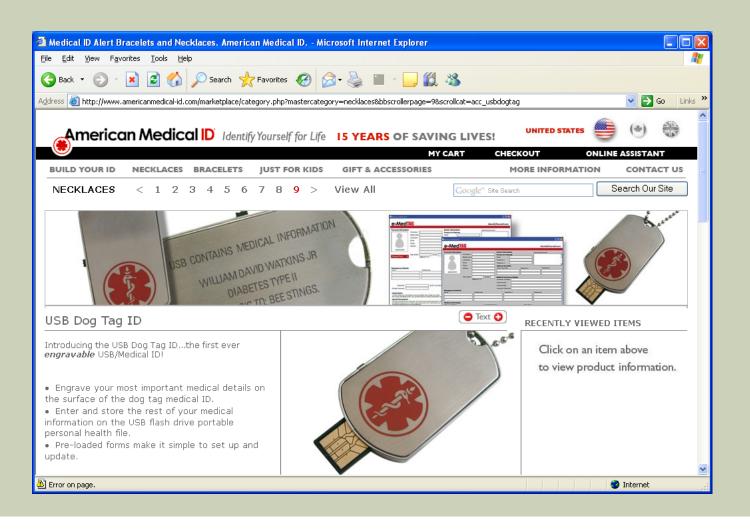
My Health Passport

http://www.sickkids.on.ca/myhealthpassport



ELECTRONIC HEALTH RECORD

HTTP://WWW.AMERICANMEDICAL-ID.COM



INSURANCE: THE GOOD, THE BAD, THE UGLY

- Insurance can be a significant barrier of transition. Uninsured rates are 29% for young adult compared with 14% national average
- There are a variety of insurance options for children and adults
- Insurance may change for our adult patients
- If a child received Medicaid/All Kids as a kid, it does not guarantee that they will be eligible as an adult
- Most dependents can now stay on insurance until they are 26 years old

HOW PROVIDERS CAN SUPPORT PATIENTS WHO LOSE INSURANCE

- Provide anticipatory guidance to plan for insurance needs as an adult. www.Healthcare.gov
- Social workers can provide resources to legal/advocacy support
 - Ex. Health & Disability Advocates can help appeal a SSI and Medicaid denial.
- Provide patient with health care clinics that see uninsured patients
- Patients without insurance may be eligible for medication prescription programs
 - Ex. <u>www.needymeds.org</u>

HEALTH INSURANCE OPTIONS

- Differs depending on state of residence
- Illinois: All Kids/Family Care (Up until 19th Birthday)
- Adult Medicaid (Income and Disability- SSI Definition)
- Medicare (Certain medical conditions)
- Private Insurance
 - Group
 - Individual (2014 can not be denied on pre-exisiting)

College/university insurance

- Illinois Comprehensive Health Insurance Plan (ICHIP) (Anyone can apply, high premiums)
- Illinois Pre-Existing Condition Insurance Plan (IPXP) (Must be uninsured for 6 months)

TOOLS: TRANSITION RESOURCES

- Lurie Children's Division of Rheumatology Transition Documents
 - Word Documents available we will let you know how to access

- Health Care Checklists
- Medical Health Summaries
- Transition Websites & Videos



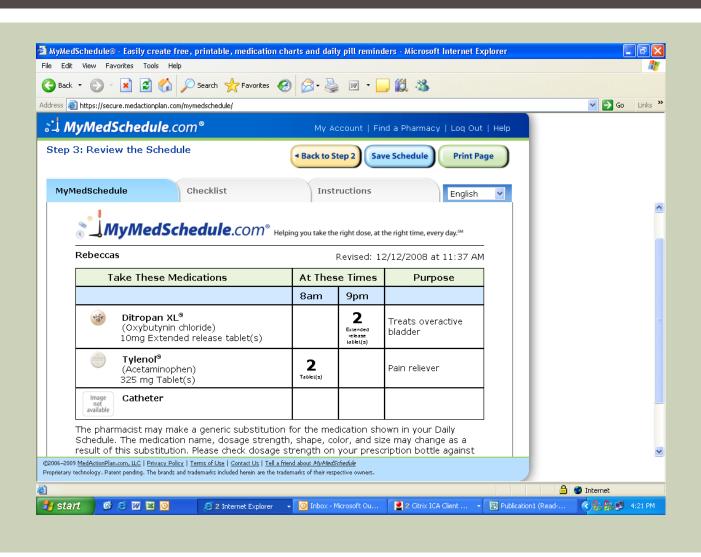
MEDICATION REMINDERS





My Med Schedule

www.mymedschedule.com



WEBSITES AND VIDEOS

Got Transition

- Got Transition/Center for Health Care Transition is a cooperative agreement between the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health
- www.gottransition.org
- http://www.gottransition.org/youthfamilies/index.cfm

Arthritis Foundation

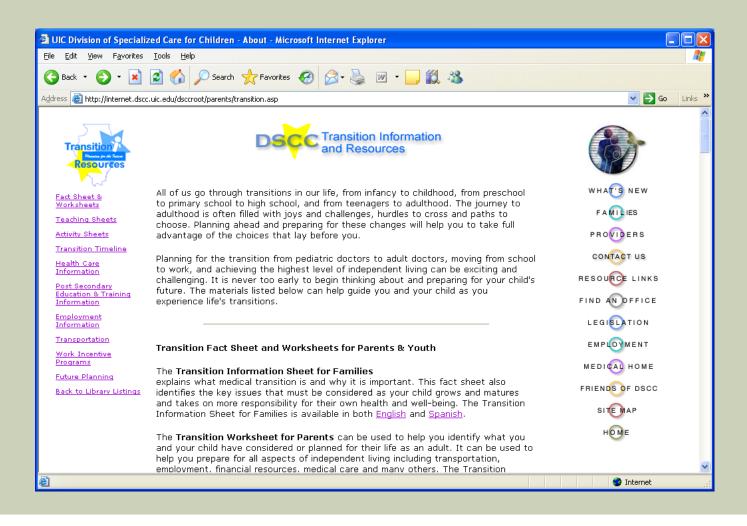
- Website is designed to prepare youth with rheumatic diseases and their families for the transition to healthy adulthood
- www.jatransition.org

WEBSITES AND VIDEOS

- http://illinoisaap.org/projects/medicalhome/transition/resources-for-physicians/
- http://www.medscape.org/viewarticle/745416
- http://depts.washington.edu/healthtr/

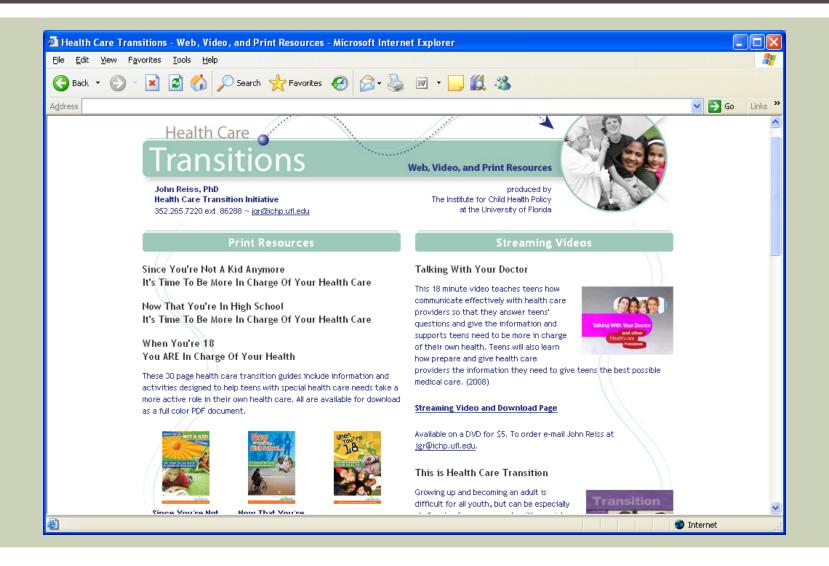
DSCC TRANSITION

HTTP://INTERNET.DSCC.UIC.EDU/DSCCROOT/PARENTS/
TRANSITION.ASP



HEALTH CARE TRANSITIONS

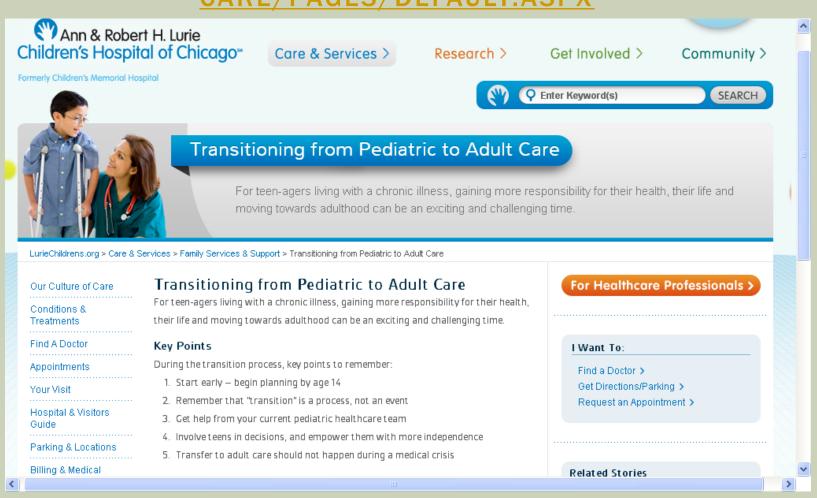
HTTP://HCTRANSITIONS.ICHP.EDU/HCT-PROMO



LURIE CHILDREN'S SITE

HTTP://WWW.LURIECHILDRENS.ORG/EN-US/CARE-SERVICES/FAMILY-SUPPORT/TRANSITIONING-TO-ADULT-

CARE/PAGES/DEFAULT.ASPX



THINGS TO REMEMBER...

- Transition involves planning for teens' future in school and work, community, relationships and medical care
- Transition is a process not an event
- Start early!
- Follow your provider's transition policy
- Use checklists and resources
- Talk with your doctor about health care transition

CONTACT INFORMATION

- Megan Curran, MD
 - mcurran@luriechildrens.org